**Title page**

# The determinants of informal caregivers' burden in the care of frail older persons: A dynamic and role-related perspective

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## Authors' contributions

dAMJ, VDT, MJ, CS and DA were involved in the study design, statistical methods, and critically interpreted the results and reviewed the article. SN and VAC critically interpreted the results and reviewed the article. dAMJ carried out the statistical calculations and drafted the manuscript. All authors read and approved the final manuscript.

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## Ethical Approval

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## Abstract

**The determinants of informal caregivers' burden in the care of frail older persons: A dynamic and role-related perspective**

Research into informal caregivers' burden does not distinguish between different stages of impairment. This study explored the determinants of burden from an in-depth perspective in order to identify which determinants apply to which phases of impairment.

**Methods**

This was a cross-sectional study including frail older persons aged 65 and above. Instruments used were the interRAI Home Care, the Zarit-12 interview and an ad-hoc economic questionnaire. A combination of variables from the Stress Process Model and Role Theory and a sub-group analysis enabled refined multivariate logistic analyses.

**Results**

The study population consisted of 4175 older persons (average age: 81.4 ± 6.8, 67.8% female) and their informal caregivers. About 57% of them perceived burden. Depressive symptoms, behavioral problems, IADL impairment, previous admissions to nursing homes and risk of falls yielded significant odds ratios in relation to informal caregivers' burden for the whole sample. These determinants were taken from the Stress Process Model. When the population was stratified according to impairment, some factors were only significant for the population with severe impairment (behavioral problems OR:2.50; previous admissions to nursing homes OR:2.02) and not for the population with mild or moderate impairment. The informal caregiver being an adult child, which is a determinant from Role Theory, and cohabitation showed significant associations with burden in all strata.

**Conclusion**

Determinants of informal caregivers' burden varied according to stages of impairment. The results of this study can help professional caregivers gain a greater insight into which informal caregivers are most susceptible to perceive burden.

**The determinants of informal caregivers' burden in the care of frail older persons: A dynamic and role-related perspective**

## Introduction

Informal caregivers play an important role in maintaining the health, well-being, functional status and quality of life of older people living at home. In addition, they are crucial partners in the care of older persons and may help them to stay at home longer. According to the World Health Organization (2008), cooperation between care professionals and informal caregivers should be the basis of primary care for older persons.

In order to understand how and under what circumstances frail older persons are able to remain at home, it is essential to take the role of their informal caregivers into account. Several studies have shown that informal caregivers' burden, also reflecting the quality of the relationship between the informal caregiver and the client, is a major predictor of institutionalization of older persons. It is also a predictor of the use of institutional services such as hospitalization and respite care (Luppa *et al*., 2010; Miller, Rosenheck, & Schneider, 2012; Spillman and Long, 2009; Spruytte, Van Audenhove, & Lammertyn, 2001).

Zarit, Reever, and Back-Peterson (1980) were the first to investigate and measure informal caregivers' burden. Later, burden was differentiated into having an objective dimension (e.g. conflicts, demanding physical help, many hours of care) and a subjective dimension (e.g. frustration, fatigue) (Montgomery, Gonyea, & Hooyman, 1985). Subjective burden is viewed as the way in which informal caregiver perceive objective burden (Zarit, Todd, & Zarit, 1986).

The Stress Process Model by Pearlin, Mullan, Semple, & Skaff (1990) views caregivers' burden as a dynamic concept. The model proposes that as impairment progresses, caregivers need to adapt to the evolving needs and changing behavior of the care receivers. In scientific literature, the Stress Process Model is the main framework for understanding the impact of impairment on informal caregivers' burden from onset up to the later stages of impairment. This model proposes that "primary stressors" like cognitive decline, behavioral problems, functional impairment and other problems related to older persons have an impact on "secondary strains" (e.g. relationship between informal caregiver and frail older person) which, in turn, can have an impact on informal caregivers' burden and on well-being. Yates, Tennstedt, & Chang (1999) used this model as a starting point, but also focused on the hours of informal care and overload, and Chappel and Reid (2002) focused on the distinction between burden and well-being.

In a recent article, Bastawrous (2013) recommended combining Pearlin's Stress Process Model with Role Theory (Biddle, 1986), in order to provide conceptual clarity. On the one hand, stress theory captures the subjective and objective domains of burden and allows for important contextual elements (e.g. care recipient impairment). Role Theory, on the other hand, facilitates our understanding of how caregiver burden may differ depending on the informal caregivers' role. Roles can differ between social family roles (e.g. caregiving, marital and parenting roles) and non-family roles (e.g. in the domains of paid work, leisure, and friendship). In this theory, role strain proposes that multiple demands placed on the person as a result of having too many roles will have negative consequences such as role overload (not having enough time or resources to manage multiple roles) and role conflict (conflicts in role expectations due to conflicting internal and external role expectations). This may lead to additional burden and psychological distress (Rozario, Morrow-Howell, & Hinterlong, 2004; Iwata and Horiguchi, 2015). Informal caregivers who care for their parents often remain in employment and also have

to take care of their own children. Occupying multiple roles may intensify role-related stress because of feeling "sandwiched" in the middle. Analyzing the contexts in which roles are taking place in the informal caregiver's situation is therefore essential to be able to analyze their burden.

The aim of this paper is to explore the significant determinants associated with informal caregivers' burden according to the different phases of impairment of frail older people.

## Methods

This was a cross-sectional study of frail older persons who were at least 65 years old and who were receiving home care interventions. These clients took part in a larger study called Protocol 3, which evaluated home care interventions aimed at keeping frail older persons at home longer. The interventions and their evaluation were described in de Almeida Mello, Van Durme, Macq, & Declercq (2012) and Van Durme *et al.* (2015). After a 2.5-day training course, professional caregivers were asked to fill out the interRAI Home Care (interRAI HC) instrument, an internationally validated comprehensive geriatric assessment (Hirdes *et al.*, 2008).

Professional caregivers also interviewed informal caregivers using an ad-hoc economic questionnaire with demographical and work-related questions (job status and left job to give care) and questions about time spent on care (total hours a week). In our study, the main informal caregiver was considered to be the person most involved in the care for the older person, meaning that they were the most involved with daily tasks or emotional support as well as spending time with the older person. This caregiver did not receive any type of remuneration and was not linked to an organization (e.g. not a volunteer). The objective burden was measured

by the number of hours per week spent providing care reported by the informal caregivers. Time spent on supervision was also included. For co-habitants, household work was not considered to be informal care if it did not take any extra time. This measurement of caregiving time was consistent with other studies (van den Berg, Brower, & Koopmanschap, 2004, Dumont, Jacobs, Turcotte, Anderson, & Harel, 2010).

The outcome variable in this study was informal caregiver burden, which was assessed by the Zarit Burden Interview 12 (ZBI12). This is a validated shorter version of the original Zarit Burden Interview questionnaire and is considered to be a reliable tool to measure self-perceived burden experienced by informal caregivers (Bédart *et al*., 2001, Higginson, Gao, Jackson, Murray, & Harding, 2010). It consists of 12 Likert scale questions with two factorial subscales (for personal strain and role strain). The scores of the ZBI12 range from 0 to 48, with a score of 10 or above indicating that the informal caregiver perceives burden.

To record factors related to Pearlin's model (e.g. functional dependence, cognitive decline, behavioral problems, incontinence) we used the interRAI HC instrument. Other factors (e.g. client's age, gender, marital status and living status) were also recorded by this instrument. Functional performance of the older person was measured by the interRAI Activities of Daily Living Hierarchy scale (ADLH) and Instrumental Activities of Daily Living Performance scale (IADLP) (Morris, Fries, Morris, 1999). Cognitive status was measured with the interRAI Cognitive Performance scale 2 (CPS2) and depression status was measured with the interRAI Depression Rating scale (DRS) (Hartmaaier *et al.*, 1995; Morris, Carpenter, Berg, & Jones, 2000). These scales are internationally validated and are automatically generated when caregivers fill out the interRAI HC instrument (Vanneste and Declercq, 2014).

Data analysis was performed in two steps using STATA 11.1 software. First, descriptive statistics were calculated in order to illustrate baseline characteristics of older persons and informal caregivers. Subsequently, in order to allow for a more in-depth analysis of the population emphasizing the distinction between differing stages of impairment, as stated in the Stress Process Model, we applied a sub-group analysis to the population of the study (Pocock, Assmann, Enos, & Kasten, 2002; Sun, Ioannidis, Agoritsas, Alba, & Guyatt, 2014). The sample was divided into three sub-populations according to exploratory sub-groups based on validated cut-offs of the interRAI scales: mild impairment (older persons with higher impairment only on IADL performance – IADLP (IADLP score≥24 and ADLH score<3 and CPS2 score <3)), moderate impairment (older persons with higher impairment on IADL performance and on ADL functioning (IADLP score ≥24 and ADLH score ≥3 and CPS2 score <3)) and severe impairment (older persons with IADL, ADL and cognitive impairment (IADLP score ≥24, ADLH score ≥3 and CPS2 score≥3) (Morris et al., 2011). After stratification, bivariate and multivariate analyses were performed for the three sub-groups as well as for the whole population of the sub-groups.

Potential stressors from Pearlin's model associated with perceived informal caregiver burden were explored for the sample by means of bivariate correlations. The following factors were taken from the interRAI instrument: ADL and IADL impairment, cognitive functioning, communication difficulties, visual problems, hearing difficulties, behavioral problems (wandering, verbal abuse, physically aggressive behavior, socially inappropriate behavior), delirium, depression, risk of falls, bladder incontinence, bowel incontinence, sleeping problems, pain, feeding problems, conflict with family, lack of family support, type of support from informal caregiver, presence of other informal caregivers, previous hospitalizations or admissions to nursing homes and house not adapted to older person. The following elements

from Role Theory were added to the analysis: informal caregiver's relation to client, informal caregiver's working status, informal caregiver left (part of) job and informal caregiver cares for other(s). A total of 37 variables were tested for bivariate correlations with informal caregivers' burden.

To analyze the relationship between primary stressors, objective burden, informal caregiver's role and perceived burden, we performed a set of logistic regression analyses. These analyses aimed to describe the pattern of relationships between variables that were revealed as being significant in the bivariate analyses. In the logistic regression, the ZBI12 score (perceived burden) was dichotomized (cut-off score 10, without burden: 0, with burden: 1).

## Results

### *Participants*

The population of the study consisted of 4175 older persons (average age: 81.4 ± 6.8, 67.8% female) and their informal caregivers (average age: 60.9 years ± 13.3). Table 1 shows the characteristics of the study population. Approximately half of the older persons were widowed (50.6%) and 43.2 % were married. The majority of the older persons did not live with their informal caregivers (60.7%). The caregivers were most often adult children (56.2 %) or spouses (30.0%). About 77% of informal caregivers who were adult children were also active in the work environment. Amongst caregivers who were spouses, only 15.2% were still working. Amongst adult children caring for their parents, 36.9% also cared for others (e.g. child or another parent). This percentage was 8.8% for informal caregivers who were spouses. About 82.8 % of the older persons were at least impaired in instrumental activities of daily living (IADL), 54.4 % needed at least extensive assistance in ADL and 34.1 % showed moderate to

severe cognitive impairment. In addition, 28.9% of the older persons had symptoms of depression and almost 13% showed behavioral problems. The majority of caregivers were retired (47.1%) or employed (29.2%). Informal caregivers reported providing emotional support (94.7%), IADL help (84.6%) and ADL help (51.0%) and according to the ZBI12 scores, 57.3 % of the informal caregivers perceived burden.

Table 1: Older persons' and informal caregivers' characteristics

| **Characteristic of older persons** | *n* | *Percentage* | *95 C.I.*[a] *LL* | *UL* |
|---|---|---|---|---|
| Mean age of older persons: 81.4 (*SD*=6.8) Median: 82.0 | | | | |
| Gender | | | | |
| male | 1545 | 32.2 | 30.9 | 33.5 |
| female | 3254 | 67.8 | 66.5 | 69.1 |
| Marital status | | | | |
| married | 1457 | 40.5 | 38.9 | 42.1 |
| widowed | 1821 | 50.6 | 48.9 | 52.2 |

| | | | | |
|---|---|---|---|---|
| single | 193 | 5.4 | 4.6 | 6.1 |
| divorced | 128 | 3.6 | 2.9 | 4.2 |
| Living status | | | | |
| non-cohabitation | 2874 | 60.7 | 59.3 | 62.1 |
| cohabitation | 1863 | 39.3 | 37.9 | 40.7 |
| Primary stressors | | | | |
| IADL dependence ≥24 | 3402 | 82.8 | 81.6 | 83.9 |
| ADL dependence ≥3 | 2512 | 54.4 | 53.0 | 55.9 |
| CPS2 scale ≥3 | 1574 | 34.1 | 32.8 | 35.5 |
| Depression scale ≥3 | 1339 | 28.9 | 27.6 | 30.2 |
| Behavioral problems present | 597 | 12.7 | 11.8 | 13.7 |
| **Characteristic of informal caregivers** | | | | |

| | | | | |
|---|---|---|---|---|
| Mean age of informal caregivers= 60.9 (*SD*=13.3) Median: 57.5 | | | | |
| Relation to client | | | | |
| Adult child | 2690 | 56.2 | 54.8 | 57.6 |
| Spouse | 1435 | 30.0 | 28.7 | 31.3 |
| Other family member | 396 | 8.3 | 7.5 | 9.0 |
| Friend | 88 | 1.8 | 1.5 | 2.2 |
| Neighbor | 88 | 1.8 | 1.5 | 2.2 |
| Other | 89 | 1.9 | 1.5 | 2.2 |
| Professional status of informal caregiver | | | | |
| Retired | 1784 | 47.1 | 45.5 | 48.6 |

| | | | | |
|---|---|---|---|---|
| Employed | 1106 | 29.2 | 27.8 | 30.7 |
| Unemployed | 155 | 4.1 | 3.4 | 4.7 |
| Other (housewife, etc.) | 743 | 19.6 | 18.4 | 20.9 |
| Type of support given to older person (more than one type possible) | | | | |
| IADL help | 3999 | 84.6 | 83.57 | 85.6 |
| ADL help | 2405 | 51.0 | 49.6 | 54.4 |
| Emotional support | 4452 | 94.7 | 94.0 | 95.3 |
| Objective burden | | | | |
| Time spent on care | | | | |
| less than 10 hours a week | 1752 | 43.3 | 41.8 | 44.9 |
| from 10 to 29 hours a week | 1110 | 29.7 | 28.3 | 31.2 |
| more than 29 hours a week | 1047 | 28.0 | 26.6 | 29.5 |
| Perceived burden | | | | |
| Zarit score ≥ 10 | 2393 | 57.3 | 55.8 | 58.8 |

[a] Note. *Cl* = confidence interval; *LL* = lower limit; *UL* = upper limit.

Bivariate analysis showed that primary stressors from Pearlin's model such as ADL, IADL, depression, cognition, behavioral problems, risk of falls, and other factors were significantly positively correlated with the burden experienced by informal caregivers. Moreover, cohabitation and time spent providing care were also positively correlated with informal caregivers' burden. The determinants from Role Theory - caring for others, the informal caregiver being the adult child and the informal caregiver having left part of his/her job - also showed a significant positive correlation. The older person's age and gender (female) were significantly negatively correlated with perceived informal caregiver burden.

*Sub-group analysis*

In order to allow for a more in-depth analysis and to account for differences in impairment levels as stated in Pearlin's model, a sub-group analysis was performed. With regard to perceived burden, sub-population 3 (severe impairment) differed significantly from the two other sub-populations ($p<0.001$). Almost 70.0% of the informal caregivers of older persons with severe impairment perceived burden versus 52.8% in the sub-population with mild impairment and 53.1% in the sub-population with moderateI impairment. Moreover, older persons with severe impairment showed the highest levels of depression (41.0%), which is significantly higher ($p<0.001$) than in the two other sub-populations (moderate impairment: 21.8% and mild impairment: 18.2%).

Subsequently, the bivariate analyses were repeated per sub-group of impairment. The burden perceived by informal caregivers was significantly correlated with cognitive impairment, IADL impairment, depression, behavioral problems, time spent providing care (objective caregiver

burden), previous admissions to nursing homes or respite care, risk of falls and cohabitation for all three sub-populations. ADL impairment was only positively correlated with perceived burden in the sub-populations with mild and moderate impairment. The fact of the informal caregiver being the adult child was positively and significantly correlated for all sub-groups. Other variables did not correlate with perceived burden in any of the sub-populations.

*Multivariate analysis*

Table 2 shows the odds ratios (*OR*) of these determinants at .05 level for the whole population and for the 3 sub-populations. In the logistic models, the significant determinants for the whole population were IADL dependence, depression, behavioral problems, risk of falls, previous admissions to nursing homes, informal caregiver being the adult child, cohabitation and conflict with family. This means that informal caregivers caring for older persons with any of these characteristics were most likely to perceive burden. For instance, informal caregivers caring for people with behavioral problems were 1.88 times more likely to perceive burden than informal caregivers of older persons who did not have behavioral problems (*OR*: 1.88, *CI*: 1.31; 2.69). As a determinant from Role Theory, if the informal caregiver was an adult child, they were 2.06 times more likely to perceive burden (*OR*: 2.06, *CI*: 1.63; 2.59). Informal caregivers living with a frail older person were 1.77 times more likely to perceive burden (*OR*: 1.77, *CI*: 1.39; 2.26) as well as informal caregivers with conflictual relationship with the older person (*OR*: 1.71, *CI*: 1.20; 2.45). Other significant factors were the risk of falls (*OR*: 1.41, *CI*: 1.17; 1.69), previous admissions to nursing homes (*OR*: 1.42, *CI*: 1.03; 1.96), frail older person with depressive symptoms (*OR*: 1.11, *CI*: 1.06; 1.16) and IADL performance (*OR*: 1.04, *CI*: 1.02; 1.05).

Table 2: Logistic regressions for determinants of perceived burden of the whole population of the study and the sub-groups of impairment

| | **Whole population** (*n*=3340) | **Mild impairment (only IADL impairment)** (*n*=1097) | **Moderate impairment (only IADL and ADL impairment)** (*n*=1309) | **Severe impairment (IADL, ADL and cognitive impairment)** (*n*=934) |
|---|---|---|---|---|
| Cohabitation | 1.77 [1.39, 2.26] .000*** | 1.83 [1.23, 2.73] .003** | 1.85 [1.29, 2.66] .001** | 1.81 [1.13, 2.89] .013* |
| IADL dependence | 1.04 [1.02, 1.05] .000 *** | 1.05 [1.02, 1.08] .000 *** | - | - |
| Depression | 1.11 [1.06, 1.16] .000 *** | - | 1.18 [1.10, 1.27] .000 *** | 1.10 [1.03, 1.19] .007 ** |
| Behavioral problems | 1.88 [1.31, 2.69] .001 *** | - | - | 2.50 [1.59, 3.93] .000 *** |
| Older person shows conflict with family | 1.71 [1.20, 2.45] .003 ** | - | 1.81 [1.03, 3.18] .039* | - |
| Risk of falls | 1.41 [1.17, 1.69] .000*** | 1.62 [1.20, 2.17] 001** | - | 1.51 [1.03, 2.22] .034 * |
| Previous admissions to nursing homes | 1.42 [1.03, 1.96] .032* | | | 2.02 [1.09, 3.73] .024* |
| Informal caregiver is | 2.06 [1.63, 2.59] .000*** | 1.82 [1.26, 2.61] .001** | 1.97 [1.38, 2.80] .000*** | 2.05 [1.29, 3.27] .002** |

adult child

*** p < .001  ** p< .01  * p< .05

For the whole population, ADL and cognitive impairment were found to be significant determinants only according to the unadjusted odds ratios (*OR*), but not when all variables were included in the model. Time spent providing care and the fact that the informal caregiver left their job to care for the older person also proved significant when no other variables were included in the model.

The results of the logistic models were refined by repeating the analyses for each of the three sub-populations. The significant determinants of burden differed between strata. Two determinants were significant for all three sub-groups of impairment: cohabitation and the informal caregiver being the adult child. The latter is an element from Role Theory.

In the sub-group with mild impairment, significant determinants were IADL performance, risk of falls, the informal caregiver being the adult child and being a co-resident. Informal caregivers caring for older persons with risk of falls showed a significant association with perceived burden (*OR*: 1.62, *CI*: 1.20; 2.17) as well as being the adult child (*OR*: 1.82, *CI*: 1.26; 2.61). Moreover, cohabitation was also associated with a higher chance of perceived burden (*OR*: 1.83, *CI*: 1.23; 2.73). Another significant determinant for this sub-group was IADL impairment but with a low OR. (*OR*: 1.05, *CI*: 1.02; 1.08).

In the moderate impairment group, the informal caregiver being an adult child was the most significant determinant (*OR*: 1.97, *CI*: 1.38; 2.80). Cohabitation (*OR*: 1.85, *CI*: 1.29; 2.66) also showed a high and significant association. Other significant determinants were conflictual relationship with family (*OR*: 1.81, *CI*: 1.03; 3.18) and depressive symptoms (*OR*: 1.18, *CI*: 1.10; 1.27).

In the sub-group with severe impairment, the presence of behavioral problems was the most significant determinant (*OR*: 2.50, *CI*: 1.59; 3.93). The informal caregiver being the adult child also showed a high association with burden (*OR*: 2.05, *CI*: 1.29; 3.27). Other determinants were previous admissions to nursing homes (*OR*: 2.02, *CI*: 1.09; 3.73), risk of falls (*OR*: 1.51, *CI*: 1.03; 2.22), cohabitation (*OR*: 1.81, *CI*: 1.13; 2.89) and depressive symptoms (*OR*: 1.10, *CI*: 1.03; 1.19).

In the model for the total population and in the models for the sub-groups of moderate and severe impairment, the value of the explained variance increased by about 36% when adding the variable from Role Theory 'informal caregiver is the adult child'. In the model for the sub-group with mild impairment, the explained variance increased by 33% after adding the same variable. This means that this addition provided more explained variance to the model, which can be considered as an advantage of using this extra variable in the analysis demonstrating an added value of combining the Stress Process Model with Role Theory.

**Discussion**

This paper explored the associations between several primary stressors, objective burden, informal caregiver's role and perceived burden. Variables examined as potential determinants were based on the Pearlin Stress Process Model and Role Theory. To our knowledge, this is the first paper to combine variables from these two models in order to investigate informal caregivers' burden.

The results were consistent with what has been found in other studies, but they are more refined. Risk of falls, depressive symptoms and behavioral problems have also shown to be significant determinants of burden (Black and Almeida 2004; Kuzuya *et al*., 2006; Taylor, Kuchibhatla, Østbye, Plassman, & Clipp, 2008), but our study showed that some determinants only applied to a certain level of impairment. Risk of falls was significant for the groups with mild and severe impairment. Depressive symptoms were significant for the sub-groups of moderate and severe impairment groups. Behavioral problems and previous admissions to nursing homes were only significant for the sub-group with severe impairment. In other words, depending on the level of impairment, the risk of caregiver burden was affected by different determinants. This is consistent with Pearlin's Stress Model, which explains that burden should be viewed as a process that progresses as impairment increases. The only common determinants for all three populations were the informal caregiver being the adult child, which is an element from Role Theory, and cohabitation.

Most studies analyze burden in a general way for a whole population of older persons. One study worked with a sub-sample in order to analyze informal caregivers' burden, but mostly focused on dementia and non-dementia diagnosis (Balducci, Melchiorre, Quattrini, & Lamura, 2008). By means of sub-group analysis, the population of this study was able to be stratified according to IADL, ADL and cognitive impairment, and we were able to explore the

determinants of burden for each level of impairment. Results showed that these determinants indeed differed across impairment levels.

Findings from the current study offer important contributions to the realm of caregiving research. In contrast to prior studies, this research showed that a combination of the Stress Process Model and Role Theory could offer a more in-depth perspective to informal caregivers' burden. These determinants should all be taken into account when developing a more comprehensive model of caregiving, along with the creation and planning of interventions and programs in order to support informal caregivers (Barbosa, Figueiredo, Sousa, & Demain, 2011). As seen in literature reviews and other studies, home care interventions can help decrease informal caregivers' burden (Adelman, Lyubov, Delgado, Dion, & Lachs, 2014; Lopez-Hartmann, Wens, Verhoeven, & Remmen, 2012; Pinquart & Sorensen, 2006).

The availability of data from comprehensive geriatric assessments such as the interRAI HC enabled many possible determinants to be explored (e.g. behavioral problems, risk of falls, previous admissions to nursing homes, among others). To our knowledge, no other study has considered so many elements (37) while analyzing informal caregivers' burden. Moreover, in comparison with other large-scale studies on informal caregivers' burden (Onder *et al*., 2008), this research comprises one of the largest study samples from one nation. This enabled us to carry out a refined sub-group analysis based on the IADL, ADL and cognitive functioning scales.

Professional caregivers can help prevent or decrease informal caregiver burden by systematically identifying informal caregivers who are at risk of burden, by taking the stages of frail older persons' impairment into account. Providing early interventions to alleviate

informal caregivers' burden and informing informal caregivers about the stressors they can expect at differing stages of impairment may help them to be better prepared for upcoming challenges in caregiving.

**Strengths**

Strengths of this research were the combination of the Stress Process Model and Role Theory explore informal caregivers' burden, the large sample size and the use of a comprehensive geriatric assessment enabling the analysis of several potential determinants and a refined stratification of the population.

**Limitations**

This study was cross-sectional. Longitudinal data would allow testing the dynamics of the change in informal caregivers' burden according to changes in older person's and informal caregiver's situation. Another limitation is the absence of information regarding the informal caregiver's gender.

**Conclusion**

Determinants of informal caregivers' burden varied based on stages of impairment. The results of the study add to the literature showing that different determinants apply for different types of impairment. Given the association of cohabitation and informal caregiver being the adult child with perceived burden for all strata of impairment, we can conclude that it is important to take both determinants into account when professional caregivers deal with frail older persons

and their informal caregivers. For the other determinants, the associations differed. Risk of falls proved to be a strong determinant for the sub-population with mild impairment, and admission to nursing homes and behavioral problems proved significant for the population with severe impairment. Conflict with family and depression were associated with burden for the population with moderate impairment. These results enable professional caregivers to gain a greater insight into which informal caregivers are most susceptible to caregivers' burden.

## Abbreviations

NIHDI: National Institute for Health and Disability Insurance

ZBI12: Zarit Burden Interview - 12 items

InterRAI HC: interRAI Home Care instrument

ADL: Activities of Daily Living

ADLH: interRAI Activities of Daily Living Hierarchy scale

IADL: Instrumental Activities of Daily Living

IADLP: InterRAI Instrumental Activities of Daily Living Performance scale

CPS2: InterRAI Cognitive Performance scale 2

DRS: InterRAI Depression Rating scale

## Conflict of interest

None

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